

# sdmny

Supported Decision-Making New York

The IDEAL School, February 23, 2022

*Kristin Booth Glen, University Professor,*

*Dean Emerita, CUNY School of Law*

*Project Director, SDMNY*



# Who are we?

- From 2016-March 31, 2021, a 5-year pilot project (largest in the US, second largest in the world!) funded by NYS Developmental Disabilities Planning Council (DDPC)
- Funded for a final “bridge year” by the Ford Foundation, the FAR Fund, and the Taft Foundation



# Guardianship

- The legal process by which the right and power to make decisions and enter into legal relationships is taken away from one person because of his/her alleged incapacity, and given instead to another, the Guardian



# Guardianship for People with I/DD in New York; Surrogate's Court Procedure Act Article 17-A

- Removes *all* legal rights from the person with I/DD (voting, marriage, ability to contract, where to live, with whom to associate, healthcare decisions, employment, etc.)
- Plenary, not “tailored” or limited like MHL Article 81
- Continues indefinitely



# Why Do Parents Seek Guardianship?

- They are told by school officials or others that it is “necessary” to get services, continue to participate in IEPs, etc.
- They see their children with I/DD as vulnerable, and believe guardianship will “protect” them
- Third parties (health care professionals, etc.) may refuse to provide services unless they are dealing with a guardian



# Does Guardianship Really Protect?

- Lack of data/evidence from “on the ground”
- Many press stories and government reports about abuses (mostly financial)
- Not a “silver bullet”
- Little or no court oversight (none under SCPA 17-A)
- Can inhibit self-determination and learning how to make good and healthy decisions that survive when parents are no longer around



# “Protection” of Persons with Intellectual Disabilities

- 1880 to 1970, institutionalization in “schools” for the retarded
  - 1964, Willowbrook
- 1966 to present, guardianship
  - 1969, Article 17-A enacted
- 2017 and forward, supported decision-making?



# Supported Decision-Making (SDM) as an alternative to Guardianship

- Persons with I/DD **never lose important rights**: e.g., to contract, to vote, to work, to marry
- SDM allows a person to take some risks and **learn from “bad” choices**
- SDM helps to **form a network of supporters** that can protect against exploitation
- Persons with I/DD have a **human right to make their own decisions**





# What Is Supported Decision-Making?

- Supported decision-making (SDM) is “a series of relationships, practices, arrangements and agreements of more or less formality and intensity designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life.”
  - Robert Dinerstein (2012)



# Supported Decision-Making can take many forms

- Completely informal (so it is often invisible)
- Circles of support
- Formalized through a facilitated process that may involve a written agreement/contract (SDMNY model)
- Legalized by statute



# Where does SDM come from?

- Our common experience of how everyone makes decisions
- The human right of every person to make her/his own decisions regardless of disability



# Everyone Uses Supports: Normalization

- When you make an important decision, how do you do it? Consulting friends and/or family? Using experts (lawyers, accountants, etc.)? Doing and utilizing research?
- People with I/DD may just need more or different kinds of support



# Steps in Decision-Making/Kinds of Support

- Gathering necessary information
- Understanding that information
- Identifying possibilities and alternatives
- Considering consequences
- Weighing the choices
- Communicating the decision to others
- Implementing the decision



# Imperatives to shift away from guardianship

- Decision making can be taught, improved; failure to utilize has negative impact, loss of capacity
- Aging caretakers, limited options
- Overburdened courts lack resources and expertise
- Increasing emphasis on “least restrictive alternative”



# And What About Human Rights?

- They give us a different, more affirmative way of looking at rights and about the place of people with disabilities in the world
- They are based in equality and non discrimination (like the *ADA*) *and*
- Dignity



# Dignity: A fundamental principle of human rights

- UN Convention on the Rights of Persons with Disabilities (CRPD), Art. 3
- General Principles:
- (3) Respect for inherent dignity, individual autonomy including the *freedom to make one's own choices...*





# U.N. Convention on the Rights of Persons with Disabilities (CRPD)

## Article 12

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to **the support they may require** in exercising their legal capacity.



# Who Supports SDM?

**2020**

- **National Center for State Courts** releases “Finding the Right Fit” training
- **Minnesota** adds SDM to guardianship statute

**2019**

- **Indiana, Nevada, North Dakota & Rhode Island** pass SDMA laws; **Maine** adds SDM to guardianship statute

**2018**

- **Wisconsin, Washington, DC & Alaska** pass SDMA laws

**2017**

- **American Bar Association** adopts Resolution 113
- **Uniform Law Commission** revises UGPPA
- **U.S. Dept. Educ. OSERS** issues guidance on transition

**2016**

- **AAIDD & The Arc** issue Joint Position Statement
- **Social Security Administration** releases Issue Brief
- **National Guardianship Association** issues Position Statement
- **Delaware** passes legislation recognizing SDMA

**2015**

- **Texas** passes legislation recognizing SDMA

**2014**

- **Administration for Community Living** creates SDM program

# Increasingly, Judges Are Asking 17-A Petitioners to Consider SDM

Reporter

2013 NYLJ LEXIS 3334 \*

Proceeding for the Appointment of a Guardian of the Person of Akiva Pursuant to SCPA, Section 17-A, in the Supreme Court, Kings County

Notice: ©  
rights res  
permission

(Proceeding  
Akiva Pu  
for the  
Pursuant  
11, 2013

## Core T

respond  
of guar  
yeshiva

disorder, travel

petitions, funds, guar

therapeutic, rabbinical, religio

interest, second wife, cross-examination,

diagnosed, requires, visits, guardianship

Judges: [\*1] Surrogate Margarita Lopez Torres

respondent would resist participation in any supportive service he, or the petitioners, would identify as necessary or desirable simply strains credulity. The respondents' father has undertaken minimal efforts, if any, to create a supported environment for each respondent that adequately addresses each individual's needs and maximizes his opportunity for growth and self-determination. Nonetheless, the respondents have in place a system, however "narrow" or limited, of what might be characterized as "supported decision-making," by which they have managed themselves and their affairs for the entirety of their adult lives.

It has not been demonstrated to the court's satisfaction that either respondent is a person with a developmental disability originating prior to the age

After a careful review of the support of the request and the factors to be considered in such fees (*Matter of Morris*, 57 Dep't 2008)), the Court has fixed at the fair and reasonable value of the legal services of the guardian ad litem, which fees are directed to be paid by the respondents' father.

This constitutes the decision and order of the court.

Date: May, 2013

Brooklyn, New York

**New York Law**

Verified objections to both petitions have been filed by the respondents' sister, Simcha (the respondents' sister, or the sister), pursuant to which neither respondent is in



# SDMNY Facilitation Process: The Cast of Characters

- The person with I/DD who we call “the Decision-Maker” or DM
- The Facilitator
- The Mentor
- The Supporters Chosen by the DM



# AT THE HEART OF SDMNY FACILITATION—THE “BIG FOUR”

- WHICH areas the DM wants to receive support (*health, finances, education, relationships, etc.*)
- WHO s/he wants to provide support in any given area (*trusted persons in her/his life*)
- WHAT kinds of support s/he wants to receive (*e.g. gathering information; explaining information, weighing pros and cons; communicating decision to third parties; implementing decision*)
- HOW s/he wants to receive the support (*logistics*)



# The three phases of SDMNY facilitation

- **Phase 1:** Facilitator works with DM on how s/he makes decisions; "mapping" decision making; creating a "Big Four" chart; identifying potential supporters;
- **Phase 2:** Facilitator works with supporters to educate them about SDM, and to "re-position" them from making decisions for, to supporting the DM in making her/his own decisions
- **Phase 3:** Facilitator works with DM and supporters to negotiate the Supported Decision-Making Agreement (SDMA) that incorporates the "Big Four"



# Phase 1: DM Facilitation

Working with the DM and utilizing “mapping” and the SDMA worksheet to ascertain:

- how the DM receives information; using “mapping” to see how decisions are made; the kinds of decisions s/he currently makes and wants to make in the future (e.g., health, money, work, education, etc.)
- who helps her/him in making decisions and who s/he would like to support her in the future (e.g., one person per area vs. circle of support)
- what kinds of support she wants to receive (gathering information, communicating decisions, helping weigh alternatives, etc.)
- how the DM wants to use her/his Supporter(s) when a decision is to be made



# Phase 2: Supporter Facilitation

Working with the DM's chosen Supporters to:

- educate them about SDM
- “reposition” them from their existing roles (such as parents who currently make decisions for the DM)
- gain their commitment to that role and to honoring the primacy of the DM in their decision-making





# Phase 3: Team Facilitation

- Working with the DM and Supporters
- Utilizing the SDMA worksheet to negotiate the supported decision-making agreement (SDMA)
- Modeling what that process should look like, with the DM at the center,
- From the first draft of the SDMA, incorporating all changes in a final agreement, which all parties understand and to which they give their assent



# A required provision in every SDMA

- That the DM has the right to revoke or change the agreement or remove and/or add supporters for the duration of the agreement



# Purpose of the SDMA

- Serves as a goal/end product for the facilitation process and signals its success
- Formalizes parties' agreement and provides a reference if misunderstandings occur
- Allows for flexibility as
  - the DM's decision-making skills and confidence increase
  - Supporters "age out" or otherwise become unavailable
  - the DM needs to make decisions in new areas
- Demonstrates that there is a clear system in place that is a "less restrictive alternative" that avoids guardianship
- Provides an evidentiary basis for passage of an SDM law in New York, and is likely to be recognized when such legislation is passed



# Legal Effect of SDMAs

- Third parties (health care professionals, bankers, etc.) *may* accept, but SDMAs are currently not legally binding on private third parties; mandatory acceptance (as with Powers of Attorney) would need legislation
- SDMA legislation is currently in place in 10 states: Texas, Delaware, Wisconsin, Alaska, Nevada, South Dakota, Rhode Island, Washington, Louisiana and Washington. D.C. but not yet in New York
- SDMA legislation, incorporating SDMNY-type facilitation introduced and passed the State Senate in June, 2021; optimistic about passage in 2022



**What is the effect of the SDMNY facilitation process on parents who otherwise might have sought guardianship?**





# Why the SDMNY model is a less restrictive alternative to guardianship

- Supported decision-making is not just a piece of paper, but an ***ongoing process***, intended to last for decades, arrived at after completion of a carefully thought out, independently evaluated facilitation ,and memorialized in a Supported Decision-Making Agreement (SDMA)between the Decision Maker and her/his chosen supporters



## But What about Protection?

- SDM creates a circle of supporters with “many eyes” to protect against abuse, exploitation or undue influence
- SDM fosters self-determination which results in being “more independent, more integrated into [the] community, better problem solvers, better employed, healthier, and better able to identify and resist abuse” National Council on Disability, *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination* (2018)



# The National Council on Disability Report continues

- “People with intellectual and developmental disabilities learn through the process of making decisions...It’s not about protecting someone. It’s about teaching them how to best protect themselves”